DOCUMENT RESUME

ED 316 969 EC 230 025

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TITLE Parental Reactions to Cleft Palate Children.
PUB DATE 86
NOTE 21p.
PUB TYPE Information Analyses (070)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Cleft Palate; Counselor Role; Eating Habits; *Mothers; *Parent Attitudes; *Parent Child Relationship; Parent Counseling; *Parent Influence; Psychologists; Speech Therapy; Therapists

ABSTRACT

This literature review examines parental reactions following the birth of a cleft lip/palate child, focusing primarily on the mother's reactions. The research studies cited have explored such influences on maternal reactions as her feelings of lack of control over external forces and her feelings of guilt that the deformity was her fault. Delays in the formation of the mother-child bond due to these reactions are evaluated, along with the impact of the parents' feelings of guilt and anxiety on the child's early emotional and social development. Other studies compare the effect of a facial defect (cleft lip) versus a hidden anomaly (cleft palate), and compare the adjustment of parents of older cleft lip/palate children with that of parents of younger cleft lip/palate children. Frustrations in the feeding process, from both the child's and the parents' perspective, are addressed. Other influences on parents' reactions, such as the amount of time which passed before being told of the condition and the way in which the mother was told, are also considered. Finally, the influence of counseling is examined, with special emphasis on the roles of the speech pathologist and psychologist. 21 references. (JDD)

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Parental Reactions to Cleft Palate Children

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Running Head: Cleft Palate

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Abstract

This paper reviews parental reactions following the birth of a cleft lip/palate child. It covers the parent's emotional reactions to the cleft lip/palate child, how and when the parent's were told of the deformity, and focuses on the duties of the Speech-language Pathologist and the Psychologist involved in counseling the parent's and the cleft lip/palate child.

Individual react to all stimuli in their environment consciously or unconsciously. Reactions to the wind upon one's face as he/she steps outside, the sound of someone's voice, the facial expressions of others, and the way a mother holds a child all cause reactions. Our minds store these reactions and call upon them when similar situations arise. Our minds then send messages that stir feelings that vary from pleasant to unpleasant. When a mother holds her newborn baby for the first time, the infant receives his/her first message containing emotion. When the infant receives this initial, emotional message, the mother-child relationship is created, thus beginning the psychosocial development and attachment and bonding of the mother to the child. Superficially, the majority of casual observers would then conclude that a child with a cleft lip/palate is victimized by the feelings of his/her parents concerning the defect and that the child is the most affected emotionally, and socially.

However, according to Madison (1986, p. 339), "As a group, children with cleft lip/palates do not have psychiatric difficulties more frequently or more severe adjustment problems than children in the general population." Other researchers strongly believe that parents are more traumatized by the congenital abnormality of their child than are the children. Therefore, the initial reactions of a parent must be addressed by the attending physician, speech-language pathologists and psychologists. These professionals aid in the parent's emotional recovery of having a child with a facial abnormality such as cleft lip/palate. A cleft lip/palate is any opening in the oral cavity, lips,

or nasal cavity that may be caused either by prenatal development failure or by accident or disease at, or following birth.

A man and woman who have joined together to form a family have ideals and expectations of what this family will be like and how they will function as a unit in society. Their attitudes and dreams are positive, their minds set on having a beautiful baby to rear, emotionally, socially, and physically. The dream sometimes shatters before it has an opportunity to become a reality. Their beautiful child is born with a cleft lip/palate. The attitudes and reactions of each mother after hearing about or viewing her child with a cleft lip/palate varies.

Though fathers' reactions are of importance, this focus of investigation is mainly on the mother's reactions to the child because of the maternal bond between a mother and a child. According to Brantley and Clifford (1980), mothers of cleft lip/palate children frequently associate their feelings toward their child according to their own personality characteristics. These researchers found that mothers' feelings concerning control or lack of control over their own lives may be important. Women who view their lives as governed by external forces might express more negative feelings toward a child born with a defect.

Mothers' reactions to their cleft lip/palate children varied, according to early investigators in the 1950's and 1960's. They discovered some mothers felt that it was their fault the child was born with a congenital deformity because of a maternal lack of proper nutrition and love needed during their pregnancy period. Others have

found that mothers show signs of disappointment along with resentment because the perfect child of which they dreamed was stolen from them.

In ASHA Reports (1965) according to Phillips when a parent is told they have a child with a cleft lip/palate, a two-fold reactions occurs. Mothers often feel responsible for the deformity, and both parents hide feelings of resentment and rejection toward the child. She also stated that this two-fold reaction has not been substantiated due to the complexity of the study of human feelings prior to giving birth to any child, whether born normal or with a facial deformity.

In several studies, cleft lip/palate children demonstrate social and emotional problems stemming from several factors. These problems may relate to speech and hearing disorders, parents' feelings of guilt and anxiety, and visible scars from surgical procedures. Parents' feelings of guilt and anxiety are of concern when considering the effects of these emotions on the cleft lip/palate child. Many factors influence the cleft lip/palate child's early emotional and social development. According to Bernstein and Kapp (1981), these are: (a) parents' feelings of guilt that the deformity was their fault, (b) parents' fears that the child may choke during feeding, (c) regular and protracted contact with physicians, and (d) supervision by anxious parents who are concerned about possible mental retardation in the child, as well as the physical defect.

Several investigations have conducted research as to how the early parent-child relationship has a subsequent effect on the cleft lip/palate child. The first area of concern is the initial reactions of the parent toward their abnormal child at birth. Many investigators deemed this

time crucial in that, if parents' reactions are negative, this may have damaging consequences for the cleft lip/palate child. These researchers have identified several initial reactions to the birth of the cleft lip/palate child. Most of these reactions have focused around the mother. Bzoch (1979) has identified some of the prominent feeling of mothers at the time of the birth of the cleft lip/palate child such as: anxiety, confusion, depression, disappointment, disbelief, frustration, grief, guilt, hurt, inadequacy, rejection, resentment, shock, stigmatization, and withdrawal.

However, "the physically intact child has a realm of interpersonal experiences, both with family members and others, which has an effect on him/her. These effects may be reflected in the child's perception of parental acceptance of him at birth" (Clifford and Brantley, 1977). A study by Slutsky (1969, p. 427), "found that 80% of the mothers reacted with strong feelings of shock, hurt, disappointment, helpless resentment and in some cases, hysteria to the event of the birth of a child with cleft deformities." Other investigators found hurt, disappointment and resentment to be the most frequent reactions to the birth of a baby with a cleft lip/palate. Although there are various thoughts as to which reactions are the strongest in a mother of a newborn cleft lip/palate infant, all the reactions are, more often than not, negative in nature, and may thus have a negative affect on the affected child (Carreto, 1981). These negative reactions could possibly affect the child's psychosocial development.

These negative feelings may cause a delay in the formation of the mother-child bond established at the time of birth. This bond is an attachment which Klaus and Kennell define "as a unique relationship between two people that is specific and endures through time" (cited in Carreto, 1981, p. 197). Investigators have reported that eye contact, touching, and holding are necessary components of the mother's attachment to her child while they foster the positive maternal feelings in the mother. According to Rubin (cited in Carreto, 1981), through eye contact, and more specifically touch and holding, the mother identifies the child's characteristics and qualities that she needs to claim the child as her own. This is usually established by the fourth week. "The mother's claiming behaviors, and those of persons significant to her, help bind the infant into the intimate social sphere of persons she claims as her own" (cited in Carreto, 1981, p. 199). The birth of a child with such a defect, according to Wirls (1971), positions the parents in a stressful situation which makes it difficult for them to carry out the social rituals that are associated with the birth of a new baby. In the absence of normal demonstrations of maternal love, parents often fail to provide alternate patterns of communication for the newborn infant to follow. Parents translate their reactions into extreme attitudes and behaviors toward their not so normal child. Wirls (1971) also reports some different parental reactions and the possible effects of these reactions:

> reactions of overanxiousness and unrealistic concern; overattention to the baby's bodily appearance and functioning; a preoccupation

with the child's handicap which may be harmful to his social and intellectual development because of a restriction of learning opportunities; rejection or overprotection; difficulty setting and maintaining realistic expectations for the child's performance and accomplishments; and difficulty enforcing discipline (p. 5).

According to Wirls, these reactions and attitudes suggest that a cleft child's psychosocial development is somewhat dependent upon the parental reactions and attitudes toward their handicapped child.

Researchers found that a facial defect, such as cleft lip, has a more profound effect on the mother than a hidden enomaly, such as a cleft palate. However, other studies indicate that there was a little difference between parents whose children had only cleft lips and parents whose children had only cleft palates. Obviously, specific reactions will vary among parents according to their own mental health, prior knowledge of such deformities and idiosyncratic characteristics. Atypical parental reactions, according to Smith (1971), may produce general anxiety among family members. This may directly affect the cleft lip/palate child in that he/she will experience an abnormal child-rearing situations, thus, causing inappropriate behavioral patterns to develop, with possible restrictions on the cleft lip/palate child's communication development.

According to Edwards and Watson (1980), generally a child's handicap affects most parent-child relationships in some way, and the most common reactions of the parents at the birth of a cleft lip/palate child are

shock and anxiety feelings. These authors, also indicate that if the mother-child bond is not formed early, and is not mutually satisfying, this may produce some problems in the child's social and intellectual development. "Those early hours after birth are known to be crucial in the mother-child bonding process" (McWilliams, Morris, and Shelton, 1984, p. 147). According to Tobiasen (1984), both the parents and the cleft lip/palate child felt, in a retrospective study, that the child's infancy and early childhood caused tension and difficulty in the family. The findings of this study indicate that congential deformity may have influenced the development of the parent-child relationship (Tobiasen, 1984). Previous studies report "that individuals with visible facial anomalies and their families often experience painful social and personal adjustments which have long lasting psychosocial adjustments" (Tobiasen, 1984, p. 131). This reflects an earlier finding indicating that psychosocial development of a cleft lip/palate child may be related to the attitudes of the cleft lip/palate child's parents, as well as, their families.

There are, however, researchers that feel that there is no real significant difference between parents of children with cleft lip/palates and parents of children who are physically normal (Edwards and Watson, 1980). Goodstein (cited in Edwards and Watson, 1980), found that parents of <u>older</u> cleft lip/palate children appeared less well adjusted to the condition than parents of younger cleft lip/palate children. This suggested that parents' reactions did not occur immediately following birth, but rather developed over a period of time. Spriestersbach

(cited in Edwards and Watson, 1980), tends to support Goodstein's findings based on his conclusion that shortly after the birth of the cleft lip/palate child there is an optimistic reaction of the parent due to the fact that surgical correction is available! Both of these researchers substantiate that parents of <u>older</u> cleft lip/palate children appear less adjusted to the condition than parents of younger cleft lip/palate children, due to the outcome of the surgical corrections, which are not as successful as they may have pictured it in their minds. "If the intervention strategies are not completely successful by the time the child reaches school age and there are resulting problems, the parents may then again become increasingly concerned with the cleft problem" (Edwards and Watson, 1980, p. 110). These studies do not indicate that a cleft lip/palate at birth may cause a psychosocial problem within the child, but rather they suggest that parents contribute to the child's psychosocial development later in the child's life.

Feeding is another area of concern that affects the mother-child bond and the cleft lip/palate child's resulting psychosocial development. Although most research fails to detect any associated psychiatric problems with children who have a cleft lip/palate, Clifford (1971), indicates "that it is commonly assumed that disfigurement, feeding difficulties, hospitalization as an infant, surgical attention to the face and/or mouth, speech defects, and parental difficulty in accepting a child with a physical defect are all adverse conditions, any one of which might lead to an evident personality disorder. The feeding problems Clifford notes directly affect the mother-child bond. Eastley (1960),

and others, consider the effects from a psychoanalytic viewpoint concerning the personality of the cleft lip/palate child. They feel these effects are due to an interference with the cleft lip/palate child's psychosexual development.

> Psychoanalytic theory has stressed the importance of the oral sensations in the personality of young children. The child obtains his first pleasurable sensations from oral contact with the mother in nursing and particular stress is placed upon the importance of contact sensations with the mouth during the very early stages of personality development or self realization. The mouth becomes a kind of organ for the interpretation of the outside world. The basic layer of personality development seems to be intimately hinged to oral experiences in infancy and very early childhood (Eastley, 1960, p. 457).

According to Ross and Johnson (1972), feeding problems are one of the most immediate problems the mother and the child encounters. This difficulty encumbers both the mother and cleft lip/palate child. Children with cleft lip, cleft palate, or both, often utilize a Break Feeder in the hospital. This feeder provides minimal sucking satisfaction, limiting the infants participation in the feeding process. Those children who have an unrepaired cleft lip/palate have difficulty in the feeding process with interruptions in the rhythm of feeding, choking, regurgitations, and much experimentation with nipples. The feeding process with cleft lip/palate children is rarely a satisfying one for the

mother or the child. The psychoanalytical theory states that if the child experiences excessive frustration in any of these psychosexual stages he/she will remain at this stage of development. Some major characteristics identified in an oral personality are an excessive need to be given love, dependency upon authorities for all kinds of support, a great fondness for food and drink, and an outlook of optimism and friendliness.

Therefore, because the cleft lip/palate child encounters frustrations in the feeding process, he/she should, based on the psychoanalytical theory, exhibit these characteristics to a greater degree than a child without the defect (Bzoch, 1971). This indicates that parental reactions hinder that child's psychosocial development during the important process of feeding the cleft lip/palate child.

Parents' reactions vary depending on how much time has passed before the mother is told of her child's condition, and how the parents is told of such a condition. Slutsky (1969, p. 428) found that "mothers suffered most when information was delayed and the baby was not shown at the expected time." It is more difficult for mothers to cope when the delay is longer because they often have preconceptualized that their baby is perfect, when in actuality there is a deformity. Slutsky (1969) also found that almost all mothers preferred to hear of the child's condition immediately following its birth. The mothers in this particular study also felt that they could sense something was wrong and in their mind's pictured something far worse than a cleft lip or palate. Slutsky's study indicated that almost all mothers would prefer their attending physician

to tell them of the problem at the time of birth. However, only 71% of mothers giving birth to cleft lip/palate children received this consideration. Some of the reasons mothers desire that their attending physicians inform them immediately is so that they can obtain accurate information on the defective condition of the child, can understand the problems yet to be faced, and to be aware of successive procedures and rehabilitative measures and resources available to them. More than 50% of the mothers in this study had no knowledge of what a cleft lip/palate was, and less than 50% of these mothers, (7 to 14 years after the cleft lip/palate child's birth), indicate no knowledge of cleft lip/palate causes (Slutsky, 1969).

Spriestersbach (cited in McWilliams, Morris and Shelton, 1984) found that one-fourth of the parents in his study were not told of their child's cleft lip/palate condition on the day of birth and that they did not even see the child on the first day. The amount of time that elapses after birth until parents learn of the cleft lip/palate affects the way a parents reacts to the condition. McWilliams, Morris and Shelton (1984) agree that the extent of the shock-like symptoms is dependent on the degree of deformity, and the length of time between the time of birth, and when the mother first views her newborn infant.

Spriesterbach (1961), warns against providing detailed counseling on the first day after the birth of the child because it is thought that the parents are unable to receive the information during the shock-like state. Noval (cited in Clifford and Crocker, 1971), cautions that parents of cleft lip/palate children may exhibit difficulty in accepting

the explanations of the physician until their anxiety has dissipated to a more manageable level. Since the time factor and severity of a cleft lip/palate influences how the parents react to the deformity, increasing or decreasing the extent of the reactions and attitudes toward the child will influence the child's psychosocial development

Counseling

Counseling will influence the extent of parent reactions and attitudes toward the deformity of their newborn infant. According to information gathered by Heller, Tidmarsh, and Pless (1981), there is little evidence that preventive services are effective; however, families of children with chronic disorders such as cleft lip and/or palate usually require counseling. In this study, Heller, Tidmarsh, and Pless (1981) found that the cleft lip/palate children themselves expressed a greater need than parents for more counseling and supportive services relating to their deformity. Few of the children in this study reported any counseling with social workers or psychologists. Also, the literature suggests that counselors frequently use the cleft-palate team approach in the counseling of the parents. The team consists of the obstetrician, pediatrician, plastic surgeon, orthodontist and prosthodontist, speech pathologist, psychologist, social worker, otolaryngologist, and audiologist. Counseling thus begins with a team of individuals working alone or together, to best provide the parents with ways of coping with the situation at hand and for the rest of their lives.

Although all of these professionals are important in family counseling, the speech pathologist and psychologist deal most directly

with the psychosocial aspects of both parents and child. The speech pathologist's job in this case is to explain to the parents the way speech and language develop normally. This way, the parents are aware of the normal development and can then identify any patterns in their child's speech that might be related to the cleft lip/palate. If the child has only a cleft of the lip and surgery was successful, it is highly unlikely that a speech problem will evolve. The speech pathologist also describes the characteristics of speech of cleft lip/palate children whose surgeries were not successful. Often a recorded sample of this type of child's speech is presented to the parents. The speech pathologist discusses the hypernasality and the articulation problems and counsels them on how will attempt to prevent this from happening to their child (Massengill and Phillips, 1975). "The speech pathologist is one of the key counselors for both the patient and his/her family from the time of the patient's birth for as long as the cleft-palate team continues to see the patient" (Massengill and Phillips, 1975, p. 27). This statement may support ideas of other researchers such as Spriestersbach (1973) and Goodstein (cited in in Edwards and Watson, 1980) who claim that parents of older cleft lip/palate children seem to be less well adjusted than those parents of younger cleft lip/palate children due to shattered hopes of successful surgery. These parents' reactions of disappointment in the surgery may be reactions to future thoughts of the child's difficulty yet to come concerning speech and language. This is where the speech pathologist's role in parent counseling is imperative.

The psychologist as a team member is responsible for helping the parents cope with the negative feelings they experience following the birth of a cleft lip/palate child. He/she can also explain what benefits psychological counseling can have for their child as well as help the parents deal with any feelings of guilt, hurt, or disappointment (Massengill and Phillips, 1975; Strauss and Broder, 1985). This counseling deals directly with the parents' reactions, attitudes, and the parents-child bond that affects the child's psychosocial development. The counseling the parents receive early on would also benefit the child's psychosocial development later. However, "advice and information offered to parents when the child is young is not transmitted to the patients themselves as they get older" (Heller, Tidmarsh, and Pless, 1981, p. 464). Therefore, psychologists should instruct the parents on how to help their child cope throughout life with obstacles to his/her psychosocial development. The counseling efforts of the team should include the parents as active participants in the treatment and decision-making process so they do not feel as if the experience they are encountering is beyond their control (Brantley and Clifford, 1979). If feelings of isolation and helplessness occur during the treatment of the child, the parents may carry this over into the child's home environment causing problems in their psychosocial development. Some researchers state that parental cooperation is essential to provide the best results for the child. Furthermore, they feel that the parents, particularly the mothers, are more in need of counseling, yet the child will be treated and not the parent or parents (Slutsky, 1969).

The emotional stability of a parent who gives birth to an infant with a facial deformity needs counseling from the professionals on a cleft palate team. Often the parents' feelings are neglected, due to the immediate problems the infant faces, such as feeding and surgical repair. Thus, parents' feelings about the deformity must be repressed until the infant has been tended to by the surgeon. Therefore, it has been indicated through research that a cleft palate team approach is the best way to confront the parent's situation, as well as the child's. When a cleft palate team approach is used in the remediation of the infant, it at the same time helps the parent's learn to cope with the immediate reactions to the infant's cleft lip/palate. The psychologist and speech pathologist assist the parents in dealing with their own feelings of guilt, disappointment, and various other attitudes and reactions toward the birth of their newborn infant. These professionals aid the parents in dealing with the lingering effects of the realization that they have not given birth to the "perfect" baby they had originally pictured in their minds.

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